Genetic Privacy Laws and Patients' Fear of Discrimination by Health Insurers: The View from Genetic Counselors

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Since 1991, over half the states have enacted laws that restrict or prohibit insurers' use of genetic information in pricing, issuing, or structuring health insurance.[1] Wisconsin was the first state to do so, in 1991, followed by Ohio in 1993, California and Colorado in 1994, and then several more states a year in each of the next five years. Similar legislation has been pending in Congress for several years.[2] Also, a 1996 federal law known as the Health Insurance Portability and Accountability Act (HIPAA) prohibits group health insurers from applying "preexisting condition" exclusions to genetic conditions that are indicated solely by genetic tests and not by any actual symptoms.[3]

This wave of legislation was prompted by rapid advances in identifying and testing for specific genetic defects that are highly predictive of future health problems, and the expectation that there would soon be an explosion of genetic information relating to a wide array of health conditions. Advocacy groups within medical genetics documented a number of cases of employers and of health, life, and disability insurers using this new-found genetic information to deny coverage, raise rates or limit the extent of coverage.[4] Fear of genetic discrimination of this sort was shown to factor strongly into patients' and family members' decisions and concerns about undergoing genetic testing.[5] Anti-discrimination laws are thus intended to achieve two kinds of social benefit: (1) to prevent unfair use of genetic information, however accurate that use might be as a source of underwriting information; and (2) to encourage more genetic testing for purposes of research, prevention, treatment, and family planning.

Another article addresses the first purpose.[6] Based on market testing and on extensive interviews in the health insurance industry and with genetic counselors, we found that there are very few documented cases of health insurers either asking for or using presymptomatic genetic test results in their underwriting decisions, either before or after these laws were enacted, or in states with or without these laws. We also documented that a person with a serious genetic condition that is presymptomatic faces little or no difficulty obtaining health insurance, and there are few indications that the degree of difficulty varies according to whether a state prohibits the use of genetic information. This article reports on the second purpose of these laws. After reviewing the methodology for this study, the article reports on whether these laws have reduced the fear of genetic discrimination by health insurers, and whether they have encouraged more genetic testing.

Journal of Law, Medicine & Ethics, 28 (2000): 245–57.

Methodology

Details of the study methodology are discussed elsewhere.[7] Briefly, a comparative case study analysis was performed in seven states (Colorado, Florida, Iowa, Minnesota, New Mexico, North Carolina, Ohio) that were selected to pair similar states with and without laws prohibiting use of genetic information in health insurance. Six of these seven states were the primary focus of this multiple case study; North Carolina played a secondary role because it was used only to field test interview guides and techniques. Because legislative activity was ongoing throughout this study, the initial selection and pairing was not wholly successful. Three states initially classified as lacking these laws adopted them in 1997, the year after the study was designed. Therefore, groupings of states were compared according to whether they had mature laws (Colorado, Minnesota and Ohio all enacted in 1995 or earlier), recent laws (New Mexico, Florida and North Carolina), or no law (Iowa). Also, the focus across all of the states was whether perceptions and

behaviors differed before and after enactment of these laws. Two states (New Mexico and North Carolina) have laws that apply broadly to all sources of genetic information, including family history, whereas the laws in the other four states apply only to information from genetic tests.

In each of the primary study states, in-depth interviews were conducted with genetic counselors and medical geneticists at most of the major medical centers that perform clinical genetics, amounting to 29 interview subjects. Most interviews were with counselors. Subjects were selected based on their degree of experience and their clinical focus, in order to include in each state clinicians who have substantial experience with both adult onset conditions and with pediatric and/or prenatal testing, and with both privately insured and Medicaid or state-assisted patients. In addition, a total of five patient advocates and one medical director from a genetic testing firm were also interviewed. Most of these interviews were conducted in-person and one-on-one and lasted an hour, although a few interviews were by phone, and some interviews lasted only 15-30 minutes or were conducted with two subjects at once. The interviews were semi-structured and in-depth based on an interview guide, but discussions were free-ranging and the coverage of topics varied. Also, various sources of documentary information were collected, including: informed consent forms and patient information brochures used by medical geneticists; published articles in academic journals and the popular press about genetic discrimination; and unpublished studies based on surveys done at genetic clinics.

These multiple sources of information and data were analyzed using both qualitative and quantitative techniques, with respect to each of these issues: patients' perceptions of the risk of genetic discrimination; the impact these fears have on decisions to undergo testing; counselors' views about whether the new legal protections adequately address these fears; and whether these protections are likely to alter patients' decisions about whether to undergo beneficial genetic testing. The concept of genetic discrimination that is used here is broader than the strictly legal definition, which is restricted to *presymptomatic* genetic information. The operative concept of discrimination we use here is any adverse effect on the ability to obtain, afford, or keep insurance, resulting from a genetic test or from genetic counseling. The focus is on whether patients' fear of insurance discrimination deters them from having genetic tests. Genetic test results can have negative consequences for insurability, even for people with clinical symptoms or current disease. Genetic tests might produce a diagnosis of symptoms that is more troubling than the symptoms themselves, or they can identify a mild disease state that is not readily observable from symptoms. Still, because of the way in which most laws are crafted, the primary focus will be on presymptomatic, predictive testing for adult-onset conditions such as breast cancer or Huntington's disease, and the focus will remain on concerns about health insurance.

Patients' Perceptions of the Risk of Genetic Discrimination

Perceptions Prior to Counseling

Most counselors we interviewed said that patients with adult-onset disorders approach genetic testing with a high level of awareness and concern about the potential for insurance discrimination.[8] For adult patients seeking testing for presymptomatic conditions, 16 of 24 counselors (67 percent) indicated their patients arrive with a high level of awareness and concern, six (25 percent) said there is some limited awareness, and only two (8 percent) indicated their patients have little or no awareness.[9] This pattern of responses is not correlated with the pattern of laws across our study states.

The level of patient concern described by one counselor reflects a high level of paranoia by some patients:

> People will call up and they won't give you their address. I can't even mail them any information because they think I am going to keep their address somewhere and distribute it to somebody. So I can't even mail them a brochure or they won't give me their phone number. They'll call and leave a message saying, "I'm calling about Huntington's. I'll call you back." Or they won't let me call them at work. They won't talk at work.

Many patients have heard about insurance discrimination from the news media.[10] A counselor at a cancer clinic explained:

> The majority of my patients are well aware of this issue. We've probably had maybe one to two patients that it was a new idea to them and they haven't thought about it. But, I've even had people hang up on the phone talking to me before they come into the clinic because it's such a big issue that they don't want the fact that we had this conversation recorded anywhere. So, it is something that I think that people are well aware of.... I'm impressed that our patients don't know what a genetic counselor is most of the time. They don't know what a medical geneticist is most of the time. They don't know anything about genetics, and there has been just as much about that in the lay literature and the newspaper and Ladies' Home Journal. But the one thing they've picked up on is the discrimination issue. They have all learned

> that. I am impressed with how well that message has gotten out to people, with very little data to back it up.

A Colorado counselor confirmed the same point, but with a wry twist:

> Q: Where do they get their information, what is the source of their fears?
> A: I think 20/20, 60 Minutes, Dateline NBC. If people are TV watchers, they know everything. People who are like from Boulder, a lot of people from Boulder don't watch TV and . . . some people say they have never heard anything about [it]. But, most people, I'll say, "What do you know about the breast cancer genes and what have you heard so far about genetic testing?" and they will say, "I'm worried about discrimination" or whatever.

Knowledge and concern by patients considering testing for Huntington's disease is especially acute. Several counselors explained that this is due to the active role that patient advocacy groups play in informing their membership of this concern. Another counselor, however, said the concern among Huntington's patients arises from their own experiences with affected family members. These attitudes contrast sharply with pediatric or prenatal genetic counseling, where all four of the counselors who spoke to this point said their patients have no prior awareness or concern about genetic discrimination.[11]

Views Conveyed During Counseling

For patients who consider genetic testing without this prior knowledge or concern about discrimination, we inquired whether counselors alert them to the possibility of genetic discrimination, and whether this is a primary source of patients' information and concern. We were told that, for pediatric and prenatal genetic testing situations, counselors rarely raise insurance discrimination as a risk of testing. This is not perceived as a significant risk, and patients are much more worried about the health of their child or a potential birth defect. Counselors view it as inappropriate to raise such tangential issues in a "crisis atmosphere" in which future insurance problems are the "last thing" on the minds of parents. Insurance discrimination is seen as tangential here because the parents who have the insurance are not the affected individual. Most counselors feel confident that the law protects newborns with congenital defects and would not allow insurers to discriminate against parents based simply on their carrier status. Several counselors had difficulty imagining how obstetric testing might lead to insurance discrimination, since this testing is done mainly to detect spontaneous mutations and so would not implicate family members. Also most people abort if the test shows a problem. These counselors also understood that, if discrimination relates to an existing condition, this will happen regardless of the genetic test and so doing a diagnostic genetic test does not worsen the patients' insurability.

Two pediatric or prenatal counselors, however, report sometimes raising insurance concerns, depending on the situation. One does so for cystic fibrosis screening because she feels that some insurers will misinterpret a carrier as someone who is affected. Another counselor is not worried about cystic fibrosis because it is such a common disease that insurers are likely aware of its genetic properties, but she feels that some concern about insurance discrimination is warranted for conditions that are rarer. For example, she is concerned that insurers may not appreciate the fact that mild forms of muscular dystrophy exist in which symptoms do not occur for many years, or they may misinterpret a hemophilia carrier as someone at risk for the disease. This counselor is also concerned that, although children are usually well protected by health insurance if their parents are healthy, when grown children come off their parents' insurance, it is often at a time when their job situation is unsettled and so they face real difficulties qualifying for insurance on their own. Both counselors agreed, however, that insurance discrimination is not sufficiently relevant to raise as an issue when testing newborns to determine the nature of potential birth defects, or when testing parents that have a fetus with a suspected defect. Only one of 14 informed consent forms we reviewed that relate to pediatric, prenatal, or generic genetic conditions mentions insurance discrimination as a risk of testing.

For adult patients, the situation contrasts sharply. The great majority of counselors, 21 of 25 (84 percent), routinely discuss the potential for insurance discrimination as a risk of genetic testing. This issue is stressed in the leading academic articles and professional practice guidelines about informed consent to genetic testing.[12] Our review of 11 informed consent forms that address adult-onset genetic conditions found that seven (64 percent) mention insurance discrimination as a potential risk of genetic testing.[13] Three of these contain only brief mention or mild notice of this risk. However, the language in four of these 11 forms contains lengthy and strongly-worded warnings, such as the following:

> If you learn that you have a genetic predisposition to breast and/or ovarian cancer, you will have knowledge that you may be forced to disclose to third parties. For example, as insurance companies learn more about hereditary risk for cancer, they may ask about the results of genetic tests of those who have or apply for coverage. In most states, life and disability insurers may ask such questions and use the answers in

underwriting decisions.... Knowledge that you have a genetic predisposition to breast and/or ovarian cancer may compromise your ability to obtain or maintain insurance coverage.

* * *

Test results indicating an inherited mutation increasing your risk for developing cancer could affect you and your family's ability to get or to keep insurance (health, life, disability). Even the fact that you are being tested could affect the insurability of both yourself and your family. You may experience loss of insurance, inability to qualify for new insurance, increased premium payments, or decreased coverage. A person may be locked into a job to keep coverage, or lose coverage in the event of a job loss.... In the course of applying for medical, life, or disability insurance, people are often asked to sign forms that give insurance companies permission to get their medical records. If you sign such a release form in the future, it is possible that... the information your doctor sends would include the results of the test and that this would affect your ability to get insurance.

Most counselors typically spend about 15 minutes of a 1-2 hour counseling session on genetic discrimination concerns,[14] although some spend only a few minutes on this, depending on the level of concern expressed by their patients and the documented potential for discrimination for the particular genetic condition.[15] Several counselors indicated that they focus on discrimination risks because of the strong culture of informed consent in the genetic testing community:[16]

A: I see some patients that come in and want to have testing and have not even thought about the insurance issue until I bring it up. It is one of the components of the information that I give during counseling, so it is kind of a routine part of my counseling with patients....
Q: If patients don't raise this on their own, then you do raise it with them?
A: Yes.
Q: Give me an example. Say I came in for colon cancer [testing] and think I may need to have this, but have not thought about this part of the issue at all, what would you tell me?
A: ... I go into how much it costs. I guess most people just naturally assume they have insurance and it will pay for it, so I have to bring up that genetic testing is fairly new and not all insurance companies cover the cost of genetic testing and also that there is some concern that having genetic testing can cause some discrimination for some people with health insurance, depending on what type of health insurance and what kind of plan that you have.... I usually get this blank stare from people like, "Oh, I didn't even think about that. I was worried about cancer and you're telling me I have to worry about that...."
Q: I gather that it is a fear in the population and it is a sufficient concern that you feel you need to warn people about it, even though there is no documented case that you know of. Do you tell them that?
A: Yes, I tell people that as far as we know to date there is no case of someone who has had their insurance dropped or raised or that they have been kicked out of an insurance policy or whatever from having the genetic testing. Again, we are talking about a short amount of time since these tests have been available, so that's why we inform people because we don't have any long term information to give people.

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Q: [Summarizing the interview so far:] So you have two sets of patients, one that comes in with some level of concern [about insurance discrimination].... Then you have another population that is less aware of it. Why don't you tell me what you advise them in the two cases.
A: There is always some basic information that I give to both groups of patients. We talk about the issues of insurability and the potential of discrimination. It is usually something that I get asked by the patients that are concerned about it, and it is an issue that I need to bring up as an issue for the other patients. The ones that ask are already aware of it, and it impacts them more, I think that it is a hard concept to get across to people that have never had insurance before, aren't used to the system, [but]... I feel compelled to bring it up. I feel it is my responsibility to do that, but I don't think it influences the final decision they make about testing.... However, if you are going to offer a test—this is the genetic counselor's bias—you don't want to do any harm. So, it has been ingrained in us [by] informed consent.

When counselors raise insurance discrimination concerns, most do not do so in an alarmist way. A large majority (16 of 22, 73 percent) note that the actual incidence of discrimination is very low, that the risks are significant only for certain types of insurance, or that there are various legal protections. Several try to reassure patients or calm their fears, somewhat. And, they describe the various confidentiality measures that are taken to help protect against this risk. However, as discussed more below, none of these counselors says there is no or an insignificant risk; all ac-

knowledge that the risk should be taken seriously for adult-onset conditions.[17] Many counselors view their primary objective as alerting patients to this potential risk. Moreover, only a few of the counselors we spoke with mention the potential positive uses of genetic test results, such as showing that someone suspected of having a genetic condition based on family history does not in fact have the gene.[18]

Counselors, however, do try to reassure patients by using several measures to enhance the secrecy of genetic test results. First, they are discreet about how they document the purposes of a visit, and where they send the test results. A visit might be described as screening for cancer, for instance, rather than genetic testing, and the test results are often not sent to the referring physician unless the patient specifically asks. Even then, counselors frequently advise the patient's regular physician not to place the results in the normal medical record. Similarly, most genetic clinics maintain separate "shadow" files that keep their records apart from the rest of the hospital's medical records.[19] Counselors explained that these measures are intended to minimize the possibility that insurers will learn of testing or test results from claims for reimbursement or from routine requests for medical records. As one experienced counselor explained, "I won't make it easy for the insurance company to get it, but I also will not deny them access to it. . . . What I will try to do is not make it easily available. By keeping it out of the medical record, it is not going to be out there for anyone to look at it."

Most of the genetic clinics we spoke with do not go so far as encouraging completely anonymous testing, in which patients have no identifying information whatsoever or use only pseudonyms.[20] Some do this with the testing lab, but they maintain accurate patient information in their files. Only one clinic offers anonymous testing when this is necessary to convince a patient to be tested. A few others, however, allow patients to give them what they strongly suspect is false identifying information.

In summary, genetic counselors use the informed consent and counseling process to alert adult patients about the risks of insurance discrimination. In doing so, although they are not alarmist, they are also not very reassuring. However, they do use a number of measures to help protect the secrecy of information about genetic testing and counseling. There is some variation in these behaviors, but, again, the variation is unrelated to the pattern of laws across our study states.

The Deterrent Effects of Discriminatory Fears

What impact do patients' discrimination concerns actually have on their decisions to undergo testing? We heard sharply contrasting views from different counselors, and for different types of patients. For pediatric and prenatal patients, almost all counselors said that insurance discrimination concerns play no role in decisions about testing, for the obvious reason that "for people that are carrying a baby or have a child with a problem, the urgency of their immediate situation is so great and they are so anxious that they will just about do any test they can to find out more specifically what is going on with their child." Another counselor explained:

> [For] children, very rarely do their parents express concern. They are just more worried about what is going on and wanting to know answers of why there are problems. For areas where we start to get into testing for adult-onset disorders, it depends on the situation. For people that we want to get tested for breast cancer because of a grandmother or aunt or someone who has passed away, it's a big issue for them. We recently saw a family where we diagnosed the second little boy with colon cancer; both kids under 12, not an issue at all when it comes to testing the other kids. It was clearly not a concern of Mom's at all. Generally, the more severe the problem, the less concerned they are with insurance. The more severe and the more immediacy of the problem, the less the concern about insurance.

For adult patients, we received a wide range of reports. A number of counselors (8 of 21, 38 percent) said that discrimination concerns are a major barrier to testing, and that large numbers of their clients decline testing, primarily for this reason.[21] One counselor, for instance, estimated that for her cancer patients, "Once I sit down with them and counsel them, I bet 80-90 percent decline proceeding with testing because of insurability." Another counselor gave a similar estimate, and two more estimated that 50 percent decline testing for insurance reasons. Where patients have discrimination concerns, all counselors said that *health* insurance is the primary concern, and the majority (13 of 22) said this was the exclusive concern. Four mentioned concerns over life insurance, one mentioned disability insurance, and four mentioned employment discrimination.

A majority of counselors (13 of 21, 62 percent), however, said that insurance concerns, while great, do not have very much actual impact on patients' final decisions about testing.[22] Four counselors said only 5-10 percent of adult patients decline testing because of discrimination concerns. One experienced counselor said, "Very seldom do we ever have a patient choose not to have testing because of insurance purposes. In fact, I cannot think of anyone. I am sure there have been some, but not that I am aware of." Another explained, "I think [insurance discrimination] is a big fear, but once people make it to the clinic it's not the reason that keeps them from getting tested. Once people decide to have the test, nothing gets in their way. Nothing. Money,

nothing." Two others explained that patients either think the actual risks of discrimination from testing are not that high, or the need to test is great enough to justify the risk:

> In Huntington's situations, people that are tested symptomatically, [discrimination from testing] is not an issue. They already have signs and symptoms. People that test before they have any signs and symptoms, usually they have additional motivating factors. They want to know before they decide to have children. We had a girl get tested before she would get married.... They have other motivating factors where they seek testing where they are not as concerned about insurance.
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> There is a good chance that this is not as big of an issue as the media makes it out to be. I talk about what are some of the other reasons for or against having the test and try and figure out if this is the major reason and maybe there is something else besides this. For some patients, it's interesting. They say, "You know, I'll take that risk. It's fine for me. My health is the major concern and I need this information."

Several other counselors confirmed that patients with prior symptoms have a greater sense of urgency to be tested and they realize that, with a history of disease already well documented, there is little risk that the genetic test itself will worsen their insurability. Thus, it appears that deterrence may be the least in the situations where there is the greatest need for testing, and the highest where testing is more discretionary. This is confirmed by our inquiries about how serious the potential harms are from not testing. We usually heard that, even when patients have symptoms, testing is often not critical to the prognosis or course of preventive treatment, for reasons explained by this counselor:

> Q: Are these people who are appropriate candidates for testing?
> A: Yes, [but] they are the ones that already know that they are at high risk. Their family histories are significant. They are already getting the [cancer] surveillance, the mammograms. In the big scheme of things, once they have talked to me, they realize that it does not really change what they are doing and risking losing their insurance with such a high risk of cancer to begin with does not really make any sense to them. So it is really a combination of, "I'm not going to change anything I am doing already and why risk that...." A lot of these genetic tests don't change treatment very much. If you have Huntington's, you have it and you can't do anything about it.... The only thing that radically changes is, for example with cancer, I can drop your risk and maybe change your surveillance and your medical management. I think cancer is the one where there might be changes in what you would do medically. ALS there is not. Huntington's there is not.

Many counselors also explained that the primary barrier posed by concerns over insurance discrimination is not outright refusal to take the test, but reluctance to seek reimbursement from health insurance for the costs of testing and counseling. The fear is that, while the secrecy measures outlined above may suffice to protect confidentiality by keeping information about testing out of the regular medical record, it would be foolish to directly notify an insurer by asking them to pay for the procedure. Thus, many patients, with the encouragement or advice of counselors, opt to pay for testing out of pocket in order to lessen the risk of discrimination by health insurers. This is the impact most often cited for Huntington's patients. Their genetic test and counseling costs $200–300, and so a number of counselors said that most Huntington's patients opt to pay out of pocket. Cancer testing and counseling costs about $2,000, and so the chances are much greater that unwillingness to notify a health insurer will result in declining the test. However, as the following counselor explained, while the reason given may be financial rather than explicit concerns over discrimination,[23] discrimination concerns often produce the financial bind:

> I think that cost is a big determinant, when you are talking about why do people refuse testing. For genetic testing for cancer, their insurance company won't pay for them and they have to pay for it themselves. They could be looking at a $2,000 bill and that seems to be much more of an issue with our patients than insurance [discrimination].... There are some people that . . . will decide to go ahead and pay for the testing themselves so as not to alert the insurance company that the testing has been done.

This helps to explain the puzzle over why health insurance is so much the focus of discrimination concerns, even though the documented record of and potential for discrimination is much lower than for life and disability insurance. Health insurance is more important to people, especially since patients and geneticists depend on health insurance to pay for testing and treatment. The reluctance to seek reimbursement for testing also explains the observation made by several counselors that people with government health insurance are much less concerned about discrimination. This includes Medicaid or state-assisted patients, and those in the military. Perhaps this reflects the fact that government insurers do not engage in medical

underwriting. Also, some counselors said that Medicaid patients are understandably much less concerned about theoretical issues of future financial protection because their focus is on more immediately pressing needs. Counselors noted that patients with more education and better jobs are the ones more likely to seek out testing where there is not an immediately pressing medical need, such as predisposition to cancer or cystic fibrosis carrier status, and that people from higher socioeconomic ranks are more likely to be in the private insurance market and to be more aware of the potential for discrimination.

Some counselors reported that the patients with the greatest reluctance to undergo testing are often family members of the primary patient and are reluctant for a number of reasons unrelated to insurance concerns. These reluctant clients are often brought in by a patient who wants them to help diagnose a potentially serious condition, but these family members themselves have not sought out genetic testing for themselves. They may not want to live with the psychological burden of information about possible future health problems, or for other reasons may be opposed to testing for purely predictive, presymptomatic conditions.[24] Pointing to potential discrimination concerns that are raised in genetic counseling gives them a more socially acceptable reason to decline, in the view of some of the more highly experienced counselors, such as the following two:

> For cancer patients it's somewhat of a different issue than I have found for some of the Huntington's patients. It's an excuse not to have testing. They really don't want it and this is one way to justify not having testing. They are coming in because everybody else in the family is pushing them to have testing. There is nothing you can do for people who have the gene for Huntington's disease. With cancer they have to weigh the risk of maybe being discriminated against, which I think is relatively minimal but it's there, against finding this information and having it be useful for their health care. So, I think some people . . . say, "I really don't want to do this." I think from a counseling standpoint it's important to figure out how much people really want this information and what they are going to do with it. That plays a much bigger role than whether or not they might be discriminated against.

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> Q: Would you make an estimate of what proportion of patients decide not to have the test because of their fear of discrimination?
> A: For Huntington's disease, I think it is really small. I think that most people have other reasons that they might not want testing and that's just one of the things they add to the pile. I've not had anybody say, "I really, really want to know. I want to know and I've got a million reasons for knowing, but the one reason why I'm not having the test is this [discrimination] issue." The people that were the most concerned about it found a way around it in that they used aliases. I really don't think that anybody is not having Huntington's testing, at least in my experience, solely because of this. . . . For cancer, I would say that it's the same. I think it's very low to almost zero. . . . I can't remember anybody that used that as their sole reason. They have all of these other reasons and that's just added to the pot.

A counter observation, however, made by several counselors, is that discrimination concerns are much less pronounced in research than clinical settings. The lesser concern in research settings can be explained by several factors. First, testing under research protocols is often not billed to insurers or patients, so the financial barriers noted above that arise from alerting the health insurer are not always present. Also, research records are less likely to become part of the regular medical record and so are less likely to be discovered through routine medical underwriting. Moreover, research protocols sometimes carry "certificates of confidentiality" from the federal government, which provide extensive protection against discovery or use of the information for unapproved purposes.[25] For these reasons, counselors perceive less risk of discrimination in research settings and give it less emphasis in their informed consent processes than in more routine clinical settings. However, our review of informed consent forms did not reveal any less attention to discrimination risks in research settings than in non-research clinical settings.

In clinical settings, other counselors said they experience a much lower level of patients declining testing, for insurance or other reasons, than is reported above. One knowledgeable counselor explained that "uptake" rates (the percent of patients who opt for testing) vary widely, from 10 to 80 percent among different clinics, depending on the style of counseling that is used. Some counselors strongly encourage testing, others emphasize the risks of testing, and others are more nondirective. This counselor felt that some cancer clinics have a much lower uptake rate than others because some counselors advise patients not to bill their insurer for the expensive testing, so many more people decline testing for combined financial and discrimination concerns.

These disparate views about the actual effect of insurance discrimination concerns make it difficult to draw any firm conclusions. One way to reconcile them is to posit that fear of discrimination is often not the dominant reason for declining testing, and that, where it is the main reason, the medical benefits of testing may not be great. The impact of discrimination fears appears strongest on those

who are being recruited to help a relative, but they are often reluctant for other reasons. Patients with a strong reason for testing are seldom deterred. These observations are consistent with one commentator's review of the disappointing uptake rates for various genetic tests:

> It appears that most people simply aren't interested in a genetic test until it becomes immediately relevant for their lives. In the case of cystic fibrosis, this usually means when they're already pregnant and worried about the health of their child.... Researchers in the five pilot studies actually sponsoring tests under the auspices of [the NIH] found that they had great difficulty even giving tests away to the non-pregnant population.... Most people were simply not interested.[26]

The most significant barrier created by discrimination concerns is cost, since those who don't trust insurers with the information are forced to pay for the counseling and testing out of pocket. While this suggests that discrimination fears would have a much stronger impact on people with less income, other indications point in the opposite direction. More affluent people tend to seek out the more discretionary kinds of tests, and discrimination concerns are much lower among those on government insurance programs such as Medicaid.

In summary, fear of insurance discrimination has a widely varying impact depending on the clinical setting and patient population. Different people with different genetic conditions have highly differentiated responses. Insurance discrimination is not a deterrent to testing when parents face pressing concerns about the health of their children or fetus. Similarly, patients seeking diagnosis for their own symptoms usually see the immediate need for the information as outweighing the risks of future discrimination, unless the information will not alter significantly their course of treatment. Discrimination concerns weigh heavily in more marginal situations, where the benefits of testing are less, or for those who are reluctant to undergo testing for other reasons. However, discrimination fears convince many patients not to submit the costs of testing to their health insurer. The resulting financial burden may add to the deterrent effect. We observed no indication that the variation in these responses bears any relation to the pattern of laws among these study states.

The Impact of Legal Protections

The focus now shifts to the legal protections. Have they reduced the perceived risks of genetic discrimination, and have they encouraged more patients to undergo testing? These questions are explored first, based on genetic counselors' awareness and knowledge of these legal protections and their views of the inadequacies of these laws. This section, then, discusses whether these laws have altered how counselors advise patients about the risks of discrimination or have altered how patients decide whether to be tested.

Counselors' Awareness, Knowledge and Views of the Law

Genetic counselors have good awareness of the legal protections against genetic discrimination by health insurers. Their awareness is somewhat better than that of the insurance agents and underwriters we interviewed.[27] Sixteen of 20 counselors (80 percent) had some awareness of the relevant state law, and 19 of 20 (95 percent) had some awareness of a federal law relating to genetic discrimination by health insurers. Although awareness is high, accurate knowledge is not. Only 12 of 20 (60 percent) of counselors had a reasonably accurate understanding of what the federal law says, and accuracy dropped to seven (35 percent) for the state laws. Of those who misunderstood the state law, almost all (7 of 9) underestimated its degree of protection, and the remainder had only a vague awareness of the state law.

The pattern of knowledge and awareness follows, to some extent, the age of the state law protections. Six of the seven counselors (86 percent) with accurate knowledge of the state laws were in states with established laws that had been in effect more than two years. All four of the counselors with no awareness of state law were in states that had enacted their law in the past year or less. Those with inaccurate knowledge but some awareness were split evenly between states with established and new laws.

We asked genetic counselors their views on how well these legal protections address concerns about insurance discrimination. No one thought the law is sufficiently protective. Instead, they pointed to a long list of defects, loopholes, and shortcomings in the law. Overwhelmingly, the most common objection (heard from 15 of 21 counselors, 71 percent) is that these laws are untested. Counselors are concerned that, until test cases are brought and there are definitive rulings from the courts establishing that vulnerable people are in fact protected, there are too many ambiguities and uncertainties for these laws to be reliable.

One counselor explained that, when a lawyer spoke to them about the state's new law, "she made it clear to us that you can write a law, but how it is interpreted only comes about when it is tested in the courts." Another counselor gave as an example the state's "stalking law" which was overturned by the courts for constitutional deficiencies: "That was one thing that made a big impact on me. It was supposed to be a protective thing for women who were being stalked by men and called police and whatever and this was going to be great. Some judge, because somebody had a lot of money and had a lawyer who was very effec-

tive, [got it] thrown out. . . ." And, another counselor thought that, despite the "ins and outs" and the "letter of the law," insurers will try to avoid covering high risks any way they can, and their general attitude is not going to change just because of the law. She cited legal protection for people with AIDS as an example where she thought the law proved to be much less protective than it was first thought to be. More than one counselor mentioned the O.J. Simpson case as an example of legal uncertainty and the advantage that comes from being able to afford the best lawyers.

Aside from the general uncertainty of any law, genetic counselors pointed to a number of specific defects, loopholes, or shortcomings in their particular state laws.[28] Some counselors would like to see the law encompass a broader range of genetic information. Seven observed that the law covers only health insurance, six noted it covers only information from genetic testing, and four mentioned that it applies only to presymptomatic situations. Others pointed to jurisdictional defects. Seven observed that the state laws do not protect people who move to another state, and seven knew that, because of ERISA preemption, state laws do not protect people in self-funded employer plans. Thus, these counselors would like to see a federal law. Still others pointed to questions about the law's permanence and enforceability. Ohio's law was enacted initially as a moratorium that was due to sunset after 10 years, so three counselors were concerned about whether its protections would extend far enough into the future to cover their current clients.[29] And two counselors noted that their state's law does not have a strong or obvious enforcement mechanism; so, it is not clear what remedies are available against violators.

The Law's Impact on Perceived Risks and on Testing Decisions

Considering all that has been said thus far, it should not be a surprise that these legal protections have had very little impact on the perceived risks of genetic discrimination, or on patients' decisions to undergo testing.

First, these laws have not changed significantly how genetic counselors approach informed consent and their warnings to patients about the risks of discrimination. Although most counselors with knowledge of the state laws at least mention these laws to patients,[30] few counselors give the legal protections much emphasis, and no counselor we spoke with is primarily reassuring about the risks of discrimination by health insurers. But all still warn their clients to some extent. Of the 11 informed consent forms we reviewed that address adult-onset conditions, only two (18 percent) mention any legal protections. One does so only briefly, and the other stresses the laws' inadequacies. It says, "In less than half the states there are laws that restrict the use that health insurers may make of [genetic] information. These laws are not comprehensive and may not protect you."

Only three of 17 counselors interviewed (18 percent) offer any reassurance based on these legal protections. These counselors give fairly detailed and accurate descriptions of the legal protections, usually in writing, and tailor the discussion to the patient's exact insurance situation (uninsured, individual, group, etc.). The rest of the counselors (82 percent) view the legal uncertainties and potential loopholes as too significant for these laws to merit any reassurance. It may be of some note that all three of those who give at least some reassurance are in states with older laws. Therefore, confidence in and reliance on the law may grow over time.

Among patients, there is similarly little indication the legal protections have had any effect. Counselors' reports about whether patients have prior awareness of the potential for discrimination does not follow any pattern that relates to the pattern of state laws. Similarly, counselors' reports about the impact this concern has on decisions to undergo testing follow no pattern that relates to the state laws. Almost none of the counselors observed any reduction in their patients' concerns about discrimination following enactment of these laws, and many noted that patients' concerns have increased recently, most likely due to more widespread publicity about the problem. However, one Colorado counselor said she had noticed a recent increase in people willing to bill their insurer for genetic testing, which may indicate some lessening of concerns. Another counselor said, "When I tell them about the law in Colorado they tend to settle down a little bit, even though I explain that there are loopholes in it."

Limitations of Study

Several limitations of this study affect the significance and generalizability of its findings. This study presents the view of genetic counselors who reflect mainly the perspective of patients who come in for counseling. Many counselors explained that most of their adult-onset patients already know about the potential for discrimination, have already considered this, and so decided to be tested by the time they come to the clinic. People with the greatest concern about discrimination never call, or they decide after only a brief phone conversation not to come in. Also, much genetic testing is done by primary care physicians who have little formal training or assistance in genetic counseling. Their behavior and impressions are likely to differ significantly. Counselors are unable to assess the full impact of discrimination fears from this broader, population-based perspective, but many thought the impact is significant. One clinic conducts an ongoing survey of people who call the clinic but never come in for counseling; it finds that insurance discrimination concerns are the primary reason.

Even from the restricted view of counselors, the focus in most interviews dealing with adult-onset conditions was on Huntington's disease or breast cancer, conditions where

positive test results are highly predictive of very serious disease and little can be done to reduce risk of disease. These conditions are likely to be atypical for many genetic tests that are eventually developed, for conditions such as heart disease, diabetes, or mental illness. For these, the predictive power may be much lower, but the ability to prevent or moderate disease higher. This alters the relevance of testing for both the patient and the insurer. Finally, counselors' reports of their patients' attitudes and decisions may not be fully accurate but may be colored by their personal views and preferences. Also, counselors' views undoubtedly shape many patients' views and behavior through the counseling process. Therefore, patient fears and decisions may be considerably different in non-counseling settings.

Nevertheless, this study has focused on the prototypical genetic conditions that gave rise to protective legislation, and it uses a key source of information that reveals whether these laws are having their intended effects. Genetic counselors are highly trained and experienced professionals in assessing patients' concerns and guiding them through their decisionmaking process. We found them to be objective, thoughtful, and sensitive observers of patients' concerns, motivations, and decisions. Therefore, their insights shed light on how patients are likely to respond in other situations.

Summary and Recommendations

Scott Burris, a professor of law and public health, warns of elevated hopes about legal protections aimed at complex behavioral and psychological phenomena such as those under study here. In his discussion of barriers to testing for HIV infection, he observes that "research and policy literature . . . display a common tendency to treat law as a simple 'tool' for influencing the complex behaviors that are seen as the proper subject of the social sciences. . . . If law does have an influence on behavior, its mechanism is likely to be every bit as complex and worthy of study as any other behavioral influence on those at risk for HIV."[31] So it is with genetic testing. In order to assume that anti-discrimination laws will increase testing, one must have some confidence in each of the following: (1) discrimination fears are significant; (2) patients will learn of these legal protections and will see them as reassuring; and (3) this reassurance will alter patients' calculus of the net advantages of testing. In his study of HIV testing, Burris documents the absence of reliable evidence on each of these points.[32] In this study, we found not just an *absence* of evidence, but considerable *contradictory* evidence on each of these assumptions.

Although genetic counselors report that their patients have great concern about insurance discrimination, many counselors think that this concern does not rank so high as the psychological impact of learning one's genetic fate, or they believe this concern is important only when the need for the information is low. Thus, discrimination concerns are often overshadowed by other barriers to testing, or by the pressing need for the information.

Where discrimination fears actually deter testing, there is little reason to believe that the legal protections so far have offered much reassurance or have altered any testing decisions. These laws provide little reassurance because counselors do not perceive them as significantly reducing the actual risk of discrimination, or counselors do not yet have sufficient confidence in these laws. These protections have not received nearly so much publicity as has the potential risk of discrimination, so patients' primary source of information about these laws is from genetic counselors. Although counselors mention these laws, they continue to place more stress on alerting patients to the potential risks than on reassuring them of the legal protections.

Thus, these laws can be, and have been, criticized from several opposing vantage points. Insurers, agents, and regulators think that genetic discrimination is not occurring in health insurance, that it is not likely to occur any time soon, and that the legal protections are excessive. Members of the genetics community (primarily, genetic counselors) think insurance discrimination is substantial and its potential is growing, and that the legal protections are low and ineffective. How might public policy respond to this polarization of views?

One remedy is to make the law greatly more protective. But the skepticism with which geneticists and others view the insurance industry suggests that this will not alter attitudes and behaviors unless the reforms are truly radical. Federalizing the state laws will still leave many of the gaps and loopholes identified by genetic counselors. Even broadening these laws to prohibit the use of predictive medical information of any kind, as proposed by Alper, et al., would have little effect since it would still leave in place other uncertainties in the scope of these laws, such as what constitutes a genetic test and when is testing presymptomatic.[33] Nothing short of either national health insurance or the complete elimination of medical underwriting would appear to address fundamentally all of these concerns. Initiating high profile enforcement actions under the existing laws to demonstrate their effectiveness would likely increase confidence in them, but there may be too few instances of actual discrimination to find any good test cases.

The other remedy is educational. Burris observes for HIV testing that "it is possible . . . that perceived risk may be reduced without reducing the actual risk. If the goal is to encourage more testing, then perceived risk, rather than actual risk, must be the primary goal."[34] For genetics, this is even more true because the actual risk may be so low that further significant reduction is not easily achievable. Thus, if the documentation is believable of a very low incidence and potential for genetic discrimination by health insurers, then the focus could be shifted from eliminating all risk to

increasing more accurate perception of the risk. A prime target for this perception is genetic counseling and informed consent policies for genetic testing. In situations where the documented and potential risks are very low, medical genetics might drop this area of concern altogether from discussions with patients. But, not discussing discrimination concerns would fail to offer the reassurance that concerned patients may need. Informed consent and counseling could emphasize the near absence of any documented harm resulting from genetic testing and the very low potential for this in view of the mounting legal protections, rather than emphasizing just the opposite.[35]

Naturally, these two remedies are not mutually exclusive. It is undoubtedly the case that federalizing the existing state laws would increase geneticists' confidence in legal protections against discrimination. Also, a prominent federal law would help to counter widespread and exaggerated publicity of discrimination risks. Moreover, such a law would not alter existing practices by health insurers or remove an essential underwriting tool, since state laws and industry practices already discourage insurers from using presymptomatic genetic information. Therefore, people on both sides of the current legislative debate will find support for their positions in these results. Outlining these possible interpretations and applications is not meant to endorse any one or more of these positions, but instead to highlight how these findings might inform ethical and political debate.

Acknowledgements

This research was supported by NIH grant R01- HG01662 from the National Human Genome Research Institute. Also participating in this research were Janice Lawlor, M.P.H., Elliot Wicks, Ph.D., Craig Richardson, Ph.D., and Jeanette Bensen, M.S., all of whom were essential to the project. This article is an expanded version of a paper previously published in *Genetics in Medicine*.

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5. E.V. Lapham, C. Kozma and J. Weiss, "Genetic Discrimination: Perspectives of Consumers," *Science*, 274 (1996): 621–24; and Department of Health and Human Services, *Health Insurance in the Age of Genetics*, July 1997.

6. M.A. Hall and S.S. Rich, "The Impact on Genetic Discrimination of Laws Restricting Health Insurers' Use of Genetic Information," *American Journal of Human Genetics*, 66 (2000):293–307.

7. *Id.*

8. See also K.J. Wingrove, et al., "Experiences and Attitudes Concerning Genetic Testing and Insurance in a Colorado Population: A Survey of Families Diagnosed with Fragile X Syndrome," *American Journal of Medical Genetics*, 64 (1996): 378–81 (reporting that 44 percent of families with positive (adverse) test results believe it will be more difficult to obtain insurance because of the testing, 31 percent are afraid to change jobs because of fear of losing health insurance, 24 percent of families have "extreme" worry over insurance issues and another 42 percent have "moderately severe" worry); and H.T. Lynch, et al., "A Descriptive Study of BRCA1 Testing and Reactions to Disclosure of Test Results," *Cancer*, 79 (1997): 2219–28 (reporting that 25 percent of patients receiving predictive genetic testing for cancer were concerned about insurance discrimination).

9. Supporting the latter view, see B.A. Bernhardt, et al., "Toward a Model Informed Consent Process for BRCA1 Testing: A Qualitative Assessment of Women's Attitudes," *Journal of Genetic Counseling*, 6 (1997): 207–22 at 215 (only three of about 75 women recruited for focus groups about breast cancer spontaneously raised potential insurance discrimination as a concern or risk of genetic testing).

10. In particular, a 1998 Parade Magazine article was mentioned by several counselors as a source of cancer patients' information and concern. For additional discussion, see P.R. Reilly, *Genetic Discrimination*, American Enterprise Institute (1997) ("hundreds of popular articles warn of genetic discrimination, relying at best on flimsy evidence").

11. This is confirmed by a 1997 mail survey of 272 genetic counselors, which found that counselors who see mostly adult patients view their patients as much more concerned about privacy and discrimination issues and are much more likely to discuss these concerns with their patients, than are counselors who see mostly pediatric or prenatal patients. C.L. Hoyle, *Discussion of Genetic Discrimination Issues by Genetic Counselors and Their Clients*, University of Cincinnati, Department of Pediatrics, Genetic Counseling Program (1997).

12. See Bernhardt, et al., *supra* note 9; P.R. Reilly, M.F. Boshar and S.H. Holtzman, "Ethical Issues in Genetic Research: Disclosure and Informed Consent," *Nature Genetics*, 15 (1997): 301–05; National Society of Genetic Counselors, "Predisposition Genetic Testing for Late-Onset Disorders in Adults," *JAMA*, 278 (1997): 1217–20; G. Geller, et al., "Genetic Testing for Susceptibility to Adult-Onset Cancer: The Process and Content of Informed Consent," *JAMA*, 277 (1997): 1467–74; American Society of Human Genetics, "Statement on Informed Consent for

Genetic Research," *American Journal of Human Genetics*, 59 (1996): 471–74; and American Society of Clinical Oncology, "Genetic Testing for Cancer Susceptibility," *Journal of Clinical Oncology* 17 (1996): 1730–36.

13. Another similar study found six of seven informed consent forms used by the leading breast cancer testing labs warn about insurance risks. S.J. Durfy, T.E. Buchanan and W. Burke, "Testing for Inherited Susceptibility to Breast Cancer: A Survey of Informed Consent Forms for BRCA1 and BRCA2 Mutation Testing," *American Journal of Medical Genetics*, 75 (1998): 82–7.

14. B.J. Baty, et al., "BRCA1 Testing: Genetic Counseling Protocol Development and Counseling Issues," *Journal of Genetic Counseling*, 6 (1997): 223–44 at 229. A group of counselors at a Utah clinic typically discuss the following list of topics in relation to testing for cancer:

- the risk of cancellation of current health, life or disability insurance;
- inability to obtain insurance in the future;
- risks may vary depending on type of policy (large group, small group, individual);
- testing may not change risk since risks due to family his tory already exist;
- the magnitude of risks is unknown;
- secrecy measures are taken, but insurers can still get in formation by asking directly about genetic tests or if the information is given to a physician who puts it in the medical record;
- a negative test result may improve the ability to get or keep insurance, but a negative result can pose problems for a relative.
- if employers learn of results, they might be concerned about future job performance or medical costs borne by their health insurance.

15. For instance, Medicaid patients and those on other government insurance programs, such as military insurance, have much less reason for concern, as discussed more below.

16. A good description of the values and culture of genetic counseling can be found in B.B. Biesecker, "Future Directions in Genetic Counseling: Practice and Ethical Considerations," *Kennedy Institute Ethics Journal*, 8 (1998): 145–60.

17. This is confirmed by a 1997 mail survey of 272 genetic counselors, which found that only 8 percent of all counselors, and 0 percent of those who see mostly adult patients, reassure patients about privacy and discrimination concerns. See Hoyle, *supra* note 11.

18. One published example can be found at Baty, *supra* note 14.

19. Only one of 10 clinics we spoke to about this declined to follow this practice.

20. For discussions debating the pros and cons, see M.J. Mehlman, et al., "The Need for Anonymous Genetic Counseling and Testing," *American Journal of Human Genetics*, 58 (1996): 393–97; W. Uhlmann, et al., "Questioning the Need for Anonymous Genetic Counseling and Testing," *American Journal of Human Genetics*, 59 (1996): 968–70; and E.W. Clayton, "Informed Consent and Genetic Research," in M.A. Rothstein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (New Haven: Yale University Press, 1997): 127–36.

21. See also Department of Health and Human Services, *supra* note 5 (at the National Institutes of Health, nearly a third of people offered a breast cancer test decline to take it, and the "overwhelming majority" of these cite concerns about privacy and health insurance discrimination as the reason); C. Lerman, et al., "BRCA1 Testing in Families with Hereditary Breast-Ovarian Cancer: A Prospective Study of Patient Decision Making and Outcomes," *JAMA*, 275 (1996): 1885–92 (16 percent of 192 people with family history of breast cancer are "very worried" about losing insurance and 18 percent are "somewhat worried"); and H.T. Lynch, et al., "An Update on DNA-Based BRCA1/BRCA2 Genetic Counseling in Hereditary Breast Cancer," *Cancer Genetics and Cytogenetics*, 109 (1999): 91–98 (the most common reason, at 37 percent, given by patients for declining predictive testing for cancer is fear of insurance discrimination). Studies like these are seriously flawed, however, because the survey format strongly encourages these answers to speculative questions about imagined behaviors and motivations, rather than testing actual behavior in response to different circumstances. This has been demonstrated in the context of testing for the AIDS virus: see S. Burris, "Driving the Epidemic Underground: A New Look at Law and the Social Risk of HIV Testing," *AIDS and Public Policy Journal*, 12 (1997) 66–78; and S. Burris, "Law and the Social Risk of Health Care: Lessons from HIV Testing," *Albany Law Review*, 61 (1998) 831–95. Thus, although numerous studies had suggested that people at risk for AIDS would greatly decrease their rate of testing if confidentiality protections were reduced, when mandatory reporting laws were implemented requiring test results to be sent to public health officials, actual testing patterns did not decline: see A. Nakashima, et al., "Effect of HIV Reporting by Name on Use of HIV Testing in Publicly Funded Counseling and Testing Programs," *JAMA*, 280 (1998): 1421. However, other researchers found that anonymous testing leads to earlier detection and medical intervention: see A. Bindman, et al., "Multistage Evaluation of Anonymous HIV Testing and Access to Medical Care," *JAMA*, 280 (1998): 1416.

22. See also Lapham, et al., *supra* note 5 (only 9 percent of 332 people in genetic support groups said, when prompted, that they or *a family member* have refused genetic testing for "fear of your insurance coverage being dropped"); Lerman, et al., *id.* (in a study of families with breast cancer history, perceived importance of the limitations and risks of genetic testing, including potential insurance discrimination, did not influence desire to have genetic testing); Lynch, et al., *id.* (describes a patient "who was extremely concerned about the possibility of insurance discrimination" but agreed to cancer testing anyway after learning about confidentiality safeguards "because she was so eager to receive her results.")

23. See also Lerman, et al., *supra* note 21 (in a study of families with breast cancer history, lacking health insurance was highly predictive of not wanting genetic testing, possibly because of the costs of follow-up treatment); H. Chaliki, et al., "Women's Receptivity to Testing for a Genetic Susceptibility to Breast Cancer," *American Journal of Public Health*, 85 (1995): 1133 (expressed willingness among general population to have breast cancer genetic test drops one-third to one-half when told that the cost of the test is more than $25); P.T. Rowley, S. Loader and R.M. Kaplan, "Prenatal Screening for Cystic Fibrosis Carriers: An Economic Evaluation," *American Journal of Human Genetics*, 63 (1998): 1160–74 (77 percent of the general population would not be willing to pay more than $25 for cystic fibrosis screening; only 6 percent would be willing to pay more than $50).

24. A good discussion of these issues relating to cancer testing can be found in Baty, et al., *supra* note 14. For discussions relating to Huntington's disease, see A.M. Codori and J. Brandt, "Psychological Costs and Benefits of Predictive Testing for Huntington's Disease," *American Journal of Medical Genetics*, 54 (1994): 174–84; K. Quaid and M. Morris, "Reluctance to Undergo Predictive Testing: The Case of Huntington's Disease," *American Journal of Medical Genetics*, 45 (1993): 41–45; S. Wiggins, et al., "The Psychological Consequences of Predictive

Testing for Huntington's Disease," *N. Engl. J. Med.*, 327 (1992): 1401–05. See also Bernhardt, et al., *supra* note 9 (only three of about 75 women recruited for focus groups about breast cancer spontaneously raised potential insurance discrimination as a concern or risk of genetic testing); Lerman, et al., *supra* note 21 (in a study of people with family history of cancer, concerns over insurance discrimination ranked no higher than four other categories of concerns, including whether the genetic test provides accurate and useful information and the psychological impact it might have on subjects or their family members); Uhlmann, et al., *supra* note 20 (people with family history of Huntington's disease ranked potential loss of health insurance as third in a list of 17 possible reasons to decline genetic testing).

25. See Clayton, *supra* note 20.

26. D.C. Wertz, "How Many People Seek Genetic Testing for Cystic Fibrosis, BRCA1, and Huntington Disease?," *Gene Letter* (May 1997), <http://www.geneletter.org/archives/testuptakes.html>.

27. See Hall and Rich, *supra* note 6.

28. Philip Reilly observes that similar attitudes prevail with respect to HIPAA as well. See Reilly, *supra* note 10.

29. The Ohio statute has since been made permanent, but in theory any of these laws could be repealed, which would open the question of whether previously acquired information would still be protected. Nothing short of a constitutional amendment would appear to address this concern.

30. Similarly, a 1997 mail survey of 272 genetic counselors found that 85 percent of those who see mostly adult patients mention state or federal protective laws to their patients. See Hoyle, *supra* note 11.

31. See Burris, *supra* note 21 at 66 and 72.

32. See Burris, *supra* note 21.

33. See Alper, et al., *supra* note 4.

34. See Burris, *supra* note 21, *AIDS and Public Policy Journal*, at 75.

35. Accord, see Reilly, *supra* note 10.